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ORIGINAL ARTICLE

PARENTAL ADAPTATION IN CARING FOR CHILDREN WITH THALASSEMIA: A META-SYNTHESIS

Erni Setiyowati[1,2]*, Ayuda Nia Agustina[3,4], Yeni Rustina[1], Allenidekania Allenidekania [1]

1. Faculty of Nursing, University of Indonesia, Indonesia
2. Nursing Department, Faculty of Health Sciences, University of Jenderal Soedirman, Indonesia
3. Nursing School, Philippine Women's University, Philippine
4. Ners Profession Program, Sekolah Tinggi Ilmu Kesehatan (STIKes) Fatmawati, Indonesia

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***Corresponding Author**
Erni Setiyowati
erni.ypb@gmail.com

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ABSTRACT

Thalassemia is a chronic disease that requires lifelong treatment. Children with thalassemia are highly dependent on their parents for daily care and management. This study aims to identify key themes reflecting the challenges, needs, and expectations of parents caring for children with thalassemia through a qualitative meta-synthesis approach based on Roy's Adaptation Model (RAM). A literature search was conducted in the PubMed, MEDLINE, Scopus, and ScienceDirect databases for English-language articles published between 2014 and 2024. Twelve studies from six countries were analyzed using the Critical Appraisal Skills Programme (CASP). The synthesis identified four meta-themes describing the parents' adaptation process: (1) physical fatigue and psychosomatic symptoms, (2) psychological stress and parental identity crisis, (3) disruption of family roles and functions, and (4) lack of systemic and social support. These findings emphasize the importance of a multidimensional support approach encompassing emotional, educational, and health policy aspects to improve family quality of life. This study provides a theoretical foundation for family-centered nursing interventions and supports parental resilience.

Keywords: *Family care; meta-synthesis; parental experience; roy's adaptation model; thalassemia*

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BACKGROUND

Thalassemia is a chronic genetic blood disorder that requires lifelong treatment, including regular blood transfusions and iron chelation therapy (Thalassaemia International Federation, 2021). In many cases, the burden of care falls primarily on parents, particularly mothers, who must adapt to the physical, emotional, and social consequences of raising a child with a life-threatening condition (Nabavian et al., 2021; Rehman et al., 2023; Shahraki-Vahed et al., 2017). The complexity and chronic nature of thalassemia not only affect the children's quality of life but also significantly impact the well-being, daily routines, and psychosocial stability of their caregivers (Rujito et al., 2023; Sevinç, 2023).

Previous studies have explored the experiences of parents caring for children with thalassemia across various sociocultural contexts. These studies consistently reveal multifaceted challenges, including emotional distress, physical fatigue, social stigma, financial strain, and limited access to professional support (Nabavian et al., 2021; Triwardhani et al., 2022). However, most existing research presents fragmented findings and lacks a comprehensive synthesis that explains these experiences through a theoretical framework grounded in nursing science.

Roy's Adaptation Model (RAM) offers a valuable framework for understanding how individuals and families respond to health-related stressors. By categorizing parental experiences into four adaptive modes—physiological-physical, self-concept, role function, and interdependence—RAM helps identify adaptive needs and guides holistic nursing interventions.

The aim of this meta-synthesis was to identify, synthesize, and categorize themes derived from qualitative studies on the experiences of parents caring for children with thalassemia, using Roy's Adaptation Model as an analytical framework. This approach is expected to provide a theoretical foundation for atraumatic, family-centered nursing care strategies that promote parental adaptation and caregiving resilience.

METHOD

Aim

This meta-synthesis aims to identify the key themes that reflect the challenges, needs, and hopes of parents caring for children with thalassemia.

Study design

The reporting of this meta-synthesis follows the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guidelines (Tong et al., 2012). This meta-synthesis has been registered in PROSPERO under the registration number CRD42024598806.

Eligibility criteria

The inclusion criteria were established based on the SPIDER principles. S (Sample) – parents or family members; PI (Phenomenon of Interest) – Experiences, care, challenges, and feelings related to caregiving; D (Design) – qualitative studies (e.g., interviews, phenomenology, ethnography); E (Evaluation) – experiences, perceptions, and views; R (Research Type) – qualitative research. Only publication in English were included. The exclusion criteria encompassed publication types such as conference proceedings, symposium and poster abstracts.

Information sources and search strategies

A systematic search strategy was conducted from October 2024 to February 2025 to identify studies examining parents' experiences in caring for a child with thalassemia. The search was carried out across five databases: PubMed, ScienceDirect, Scopus, ProQuest, and EBSCO. Inclusion criteria were restricted to articles published between 2014 and 2024. The search strategy utilized the following combination of keywords:

- **Sample:** "parents" OR "family" OR "caregivers"
- **Phenomenon of Interest:** "experience" OR "care" OR "challenge" OR "coping"
- **Design:** "qualitative" OR "phenomenology"
- **Evaluation:** "perception" OR "view"
- **Research Type:** "qualitative" OR "mixed-method"

This comprehensive search approach was designed to identify relevant qualitative and mixed-method studies, providing valuable insights into the lived experiences of parents managing the care of children with thalassemia.

Literature search outcome

A total of 191 articles were retrieved from five databases: 28 articles from EBSCO, 67 from ProQuest, 64 from Scopus, 17 from ScienceDirect, and 15 from PubMed. Thirty-five duplicate articles were removed. Subsequently, 148 articles were excluded for the following reasons: population (n = 52), publication type (n = 49), outcome (n = 27), study design (n = 17), and publication time (n = 3). An additional five articles were identified through citation searching. After screening, one article was excluded because it was not published in English. The final number of articles included in the analysis was 12 (Figure 1).

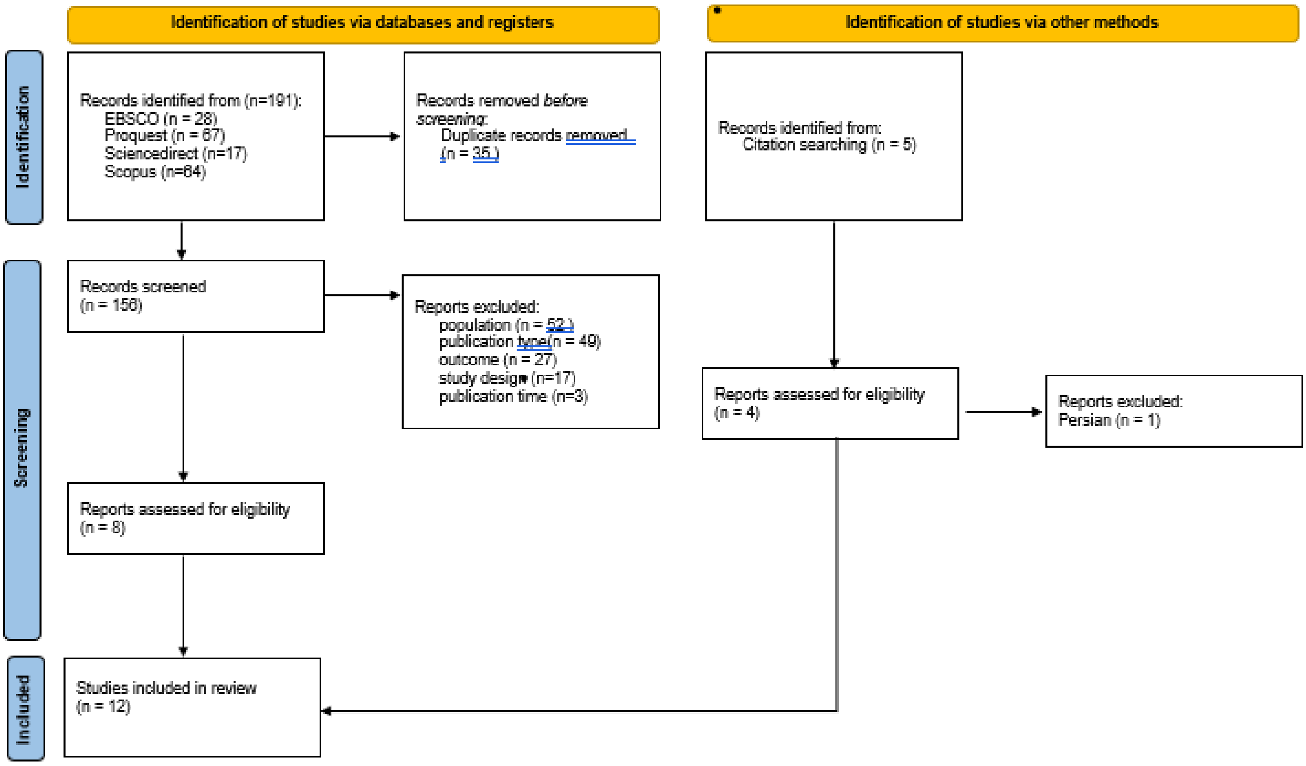

Figure 1. Study Flow Diagram

This qualitative study conducts a meta-synthesis of 12 eligible studies,all published between 2014 and 2024. The combined sample included 249 participants from six countries: Indonesia (n=1), Iran (n=6), Pakistan (n=2), Turkey (n=1), Papua New Guinea (n=1), and Jordan (n=1). Among the participants, there were 93 parents, including 148 mothers, 7 fathers, and 1 grandmother. The studies employed various research designs, including phenomenology (n=7) and qualitative content analysis (n=5) (see Table 2.)

The synthesis of twelve qualitative studies exploring the experiences of parents caring for children with thalassemia major revealed complex adaptive processes, which can be understood through the four adaptive modes of the Roy Adaptation Model (RAM): physiological–physical, self-concept, role function, and interdependence. Each mode reflects adaptive or maladaptive responses to the stressors encountered by parents during their caregiving journey (see Figure 2). In this synthesis, maladaptive responses predominated across all modes, characterized by physical exhaustion, psychological distress, role disruption, and social isolation. Although less frequently reported, adaptive responses included seeking social support, relying on spiritual faith, and utilizing positive coping strategies.

Study selection and quality appraisal

In the first step, all duplicate articles were removed. Subsequently, two reviewers (ES and AY) screened the titles and abstracts to identify studies eligible for inclusion in our review. Literature reviews, quantitative studies, and research that did not involve parents of children with thalassemia were excluded. The two reviewers then retrieved the full-text versions of the remaining articles and assessed their eligibility using the Critical Appraisal Skills Programme (CASP) (Table 1.) The eligible articles were then discussed with researchers YR and AL to proceed with to next step, which involved conducting the meta-synthesis.

Table 1. Critical Appraisal

Reference	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Score
(Dewi et al., 2024)	Y	Y	Y	Y	Y	Y	Y	C	Y	Y	9,5
(Rehman et al., 2023)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
(Nabavian et al., 2022)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
(Shahraki-Vahed et al., 2017)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9.5
(Nabavian et al., 2021)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9,5
(Abu Shosha & Al Kalaldeh, 2018)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
(Nagiria et al., 2021)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9,5
(Karakul et al., 2022)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
(Heidari & Ahmadi, 2020)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9.5
(Pouraboli et al., 2017)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10
(Ishfaq et al., 2015)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9,5
(Heidari et al., 2018)	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	9,5

Q1 Was there a clear statement of the aims of the research?
Q2 Is a qualitative methodology appropriate?
Q3 Was the research design appropriate to address the aims of the research?
Q4 Was the recruitment strategy appropriate to the aims of the research?
Q5 Was the data collected in a way that addressed the research issue?
Q6 Has the relationship between researcher and participants been adequately considered?
Q7 Have ethical issues been taken into consideration?
Q8 Was the data analysis sufficiently rigorous?
Q9 Is there a clear statement of findings?
Q10 How valuable is the research?
Y=YES C=Can't Tell N=NO

RESULT

Characteristics of the included literature

These 12 studies included a total of 249 parents of children with thalassemia. Table 2 provides detailed characteristics of the included studies, summarizing key information about the authors, countries, methodologies, data collection methods, participants, phenomena of interest, and qualitative findings.

Table 2. Characteristics of study

No.	First Author & Year	Article Title	Country	Methodology	Data Collection & partisipans	Phenomenon of Interest	Qualitative Findings
1	(Dewi et al., 2024)	Exploring Experiences of Mothers of Children with Thalassemia	Indonesia	Descriptive phenomenological	Semi-structured interviews, 11 mothers	Experiences of mothers caring for children with thalassemia	Theme 1: Perception of thalassemia as a genetic condition. Categories: a. Anemia and Hereditary Disease; b. Physical Symptoms; c. Fatigue, Dizziness, and Paleness. Theme 2: Emotional, logistical, and practical caregiving challenges. Categories: a. emotional distress; b. logistical difficulties in accessing care: c. practical issues

No.	First Author & Year	Article Title	Country	Methodology	Data Collection & partisipans	Phenomenon of Interest	Qualitative Findings
							related to medication management and dietary restrictions. Theme 3: Support received by mothers in caring for children with thalassemia. Categories: a. Husbands' Involvement in Medical Treatment and Blood Donor Searches; b. Teachers' Support for Children's Activities; c. Friendly and Supportive Healthcare Providers.
2	(Rehman et al., 2023)	Challenges of Having a Child with Thalassemia in Pakistan	Pakistan	Descriptive phenomenological	Interviews, 21 parents	Experiences of parents of children with thalassemia related to their family, financial, social, treatment, and psychological issues	Theme 1: challenges related to diagnosis and treatment. Subtheme: a. Need for a screening test for β-thalassemia mayor (β-TM); b. β-TM symptoms at the time of diagnosis and diagnosis variation; c. Challenges in blood arrangement; d. Theotherapy/ faith healing as a challenge for treating child. Theme 2: physical/socio-emotional distress and daily parenting challenges. Sub themes: a. Physical and socio-emotional distress; b. Adherence to prolonged treatment. Theme 3: financial and familial challenges. Sub theme: a. Financial; b. Familial.
3	(Nabavian et al., 2022)	The Psychosocial Challenges of Mothers of Children with Thalassemia	Iran	Phenomenological	In-depth interviews, 14 mothers	Psychosocial challenges of mothers	Theme 1: Psychological distress. Subthemes: a. emotional exhaustion; b. Mental strain; c. social stigma. Theme 2: Bodily burnout. Subthemes: a. Acute psychosomatic reactions; b. Long-term psychosomatic consequences Theme 3: Mothers' need to empathy and support. Subthemes: a. Expectation of family support; b. Support needs outside the family

No.	First Author & Year	Article Title	Country	Methodology	Data Collection & partisipans	Phenomenon of Interest	Qualitative Findings
4	(Shahraki-Vahed et al., 2017)	Lived Experiences of Iranian Parents of Beta-Thalassemia Children	Iran	Descriptive phenomenological	Purposive sampling and interviews, 15 parents	Lived experiences of Iranian parents	Theme 1: Gray marriage consanguinity Theme 2: Burdened with increased number of children with thalassemia Theme 3: Socio-familial worries Theme 4: Inexpressible wishes for having an ideal society
5	(Nabavian et al., 2021)	A Qualitative Study Exploring the Experiences of Mothers Caring for Their Children with Thalassemia in Iran	Iran	Qualitative content analysis	Semi-structured interviews, 14 mothers	explore the experiences of mothers caring for their children with thalassemia	Theme 1: Physical distress. Subthemes: a. Maternal physical problems; b. Physical weakness and exhaustion. Theme 2: Psychological suffering. Subthemes: a. *Confusion; b. Painful emotions.* Theme 3: Hellish life. Subthemes: a. Restless life; b. Involvement in a painful caring process; c. Turmoil in the family. Theme 4. Self-negligence. Subthemes: a. Disregarding for the occurrence of psychosomatic illnesses; b. Neglecting of one's health.
6	(Abu Shosha & Al Kalaldeh, 2018)	Challenges of having a child with thalassaemia major: a phenomenological study	Jordan	descriptive phenomenological	Semi-structured, face-to-face interviews, 23 mothers	explore challenges facing Jordanian mothers when having a child with thalassaemia major	Theme 1: Unprecedented psychosocial distress. Subthemes: a. Overwhelming psychological feelings; b. Self-dispraising; c. Concern for the child’s future; d. Mothers’ social alienation. Theme 2: Additional financial burden. Subthemes: a. Meeting the cost of care; b. Risk of job termination. Theme 3: Deficiency in knowledge and its sources. Subthemes: a. Deficient knowledge about the disease; b. Lack of sources of knowledge.
7	(Nagiria et al., 2021)	Living with Thalassemia in Papua New Guinea: The Experience of Children, Adolescents,	Papua New Guinea	Mixed-methods longitudinal study	Serial interviews, 21 families	Describe the quality of life of affected children and adolescents and the experience	Theme 1: Challenges in Access to and Delivery of Care. Theme 2: Physical and Psychosocial Impact on Children.

No.	First Author & Year	Article Title	Country	Methodology	Data Collection & partisipans	Phenomenon of Interest	Qualitative Findings
		and Their Families				of and difficulties faced by their parents in the setting of a tertiary referral hospital in PNG.	Theme 3: Burdens and Sacrifices of Families. Theme 4: Lack of Support from the Healthcare System. Theme 5: Positivity and Resilience of Families.
8	(Karakul et al., 2022)	Experiences of Parents of Children with Thalassemia Major in Turkey	Turkey	Qualitative phenomenological	Semi-structured interviews, 14 parents	experiences of parents of children with Thalassemia Major	Theme 1: Unprecedented psychosocial distress. Sub-themes: shock, sadness, fear, stress, depression, death anxiety, fatigue, and burnout. Theme 2: social support. Sub-themes: mother, spouse, no social support Theme 3: financial burden. Sub-themes: treatment, transportation, and living costs. Theme 4: concern about children in the future Sub-themes: life, university, and working.
9	(Heidari & Ahmadi, 2020)	Explaining Consequences of Parents Having Child with Thalassemia	Iran	Inductive qualitative approach	Semi-structured interviews, 15 parents	explain the consequences of parents who have children with thalassemia	Theme 1: non-acceptance of disease. Sub-themes: disbelief, lack of following up treatment, and interest in abortion. Theme 2: Parent Psychological Reactions. Sub-themes: unhappiness, anxiety, and mental confusion. Theme 3: Isolation. Sub-themes: dissociation and stigma.
10	(Pourabol i et al., 2017)	The Burden of Care: Experiences of Parents of Children with Thalassemia	Iran	Content analysis	Semi-structured interviews, 22 parents	Burden of care among Iranian parents	Theme: Parents' Burden of care. Categories: immersion in suffering, stigma and social death, uncertainty about the future, and absence of a support network.
11	(Ishfaq et al., 2015)	Mothers' Awareness and Experiences of Having a Thalassemic Child	Pakistan	Focus group discussions	FGDs with semi-structured guide, 64 mothers	Mothers' awareness and experiences with thalassemia	Theme 1: Belief about the Child's Disease. Sub-themes: religious faith, cousin marriage, childhood illness, mother responsible. Theme 2: Awareness and Knowledge of Thalassemia. Sub-themes: inherited disease, blood transfusion

No.	First Author & Year	Article Title	Country	Methodology	Data Collection & partisipans	Phenomenon of Interest	Qualitative Findings
							and medications, knowledge gaps. Theme 3: Impact of Thalassemia on the Child and Family. Sub themes: child impacts, chronic ailment, disease treatment, social and emotional impacts. parental impact: financial, emotional, and social, weakness in parental relationships. Theme 4: Prevention and Future Concerns. Sub-themes: preventive mechanism, pre-marital screening, educational programs. future concerns, hope for a cure, availability of blood.
12	(Heidari et al., 2018)	Stress Management Experience of Caregivers of Thalassemia Children	Iran	Phenomenological qualitative	Semi-structured interviews, 15 participants (10 mothers, 4 fathers, 1 grandmother)	explain stress management in caregivers with thalassemia children	Theme 1: seeking for hope. Subcategories: seeking hope, trusting in God Theme 2: seeking information. Subcategories: seeking information from parents, seeking information from physicians and nurses. Theme 3: seeking new treatments. Subcategories: seeking new treatment, seeking transplant.

Themes

1. Meta-theme: Physical exhaustion and psychosomatic consequences

Sub-theme: Caregiver fatigue and exhaustion

Parents, particularly mothers, reported significant physical impacts resulting from the intensive care demands of their children. Common symptoms included chronic fatigue, sleep disturbances, and overall health deterioration.

> "*I feel a strange tiredness that has made me weak, I was very active before, but not now "(Navabian et.al, 2021)*
> "*I do not have the time and ability to take care of myself at all. I became weak from inside. I used to be active, but now I suffer from pain in my hands and feet, migraine headaches, and so on" (Navabian, et.al, 2022)*

Sub-theme: Psychosomatic symptoms

In several studies (Nabavian et al., 2021; Pouraboli et al., 2017), parents described being “immersed in suffering,” often neglecting their own physical needs to prioritize their child’s care. Some experienced psychosomatic symptoms, such as headaches and back pain, triggered by prolonged emotional stress (Abu Shosha & Al Kalaldeh, 2018; Nabavian et al., 2021).

> *I have all kinds of chronic diseases, such as high blood pressure and diabetes, due to these stresses. I also have a heart problem recently” (Nabavian et al. (2022)*

> *"I now have a headache, stomachache, and heart disease. Sometimes I am so upset that as if acid has been poured into my stomach. It is so difficult to take care of an ill child that my hands hurt. I can no longer do housework (Navabian et.al., 2021).*

2. Meta-theme: Psychological distress and parental identity crisis

Sub-theme: Negative emotional responses

The diagnosis of thalassemia in a child often triggers profound emotional responses that disrupt parents' self-concept. Feelings of guilt, helplessness, and fear of the future are common, particularly when the illness is linked to consanguineous marriage or genetic factors (Ishfaq et al., 2015; Shahraki-Vahed et al., 2017).

> *"I am worried; I'm always scared that something might happen to my child. When I ask other mothers, they say that we are all the same, we are depressed, we cannot control the bad thoughts ..." (Heidari et.al, 2020)*
> *I cannot stop crying, I cannot tolerate this . . . I am the person responsible for making her sick . . .I am guilty" (Shosha, et.al, 2018)*

Sub-theme: Stigmatization and social exclusion
In culturally sensitive settings, parents experienced societal stigma, which lead to feeling of shame, self-blame, and social withdrawal (Heidari & Ahmadi, 2020; Rehman et al., 2023). These conditions triggered internal conflict and doubt about their identity and adequacy as parents.

> *I have several years of experience. Many mothers feel ashamed of their child's illness and even they feel ashamed that they even hide the child's illness from a very close family" (Heidari et.al, (2020)*
> *"People stigmatize us. Unfortunately, that is how they perceive thalassemia and blame this disease" (Pouraboli et al. (2017)*

Sub-theme: Spiritual and emotional coping
Despite these challenges, spiritual beliefs and religious faith served as sources of resilience and hope for some caregivers (Heidari & Ahmadi, 2020). A strong sense of spiritual acceptance and submission to divine will emerged as a coping mechanism among parents of children with thalassemia. Faith in God's plan provided them with emotional strength and a framework for understanding their child's illness, viewing it not merely as a medical condition but as part of a predetermined divine destiny to be faced with patience and trust.
As one participant expressed:

> *'Humans do not have the power to do anything without the will of Allah. all planned and written that what is going to happen; we just act accordingly so do the disease of my child was also written. Everything in this world is fragile and has to come to its eternal end. The real world is the hereafter' (Ishfaq et al., 2015).*

Similarly, another parent expressed a profound sense of surrender and reliance on God's will:

> *"My child is small, and it was very difficult for me if he would be injected with Desferal. Thank God we give him tablets, and he has no problem. Only the phlebotomy bothers him, but that's just once a month. If it is God's will, he will receive a transplant. If not, we have to manage the situation. Let's see what God wants…" (Heidari et al., 2018)*

3. Meta-theme: Role disruption and challenges in family functioning

Sub-theme: Role overload and daily care demands
Caregiving responsibilities disrupted parents' ability to fulfill their social and occupational roles. Many had to reduce their work hours or abandon employment altogether to accompany their children to blood transfusions and medical treatments (Karakul et al., 2022; Pouraboli et al., 2017).

> *I'm working in a private company, and I have to take unpaid leaves frequently or unpaid vacations during my child hospitalization, I have to work and support my husband to cover all the expenses for our child (Shosha, et.al, 2018)*

Sub-theme: Family conflict and dysfunction
In some families, marital relationships and sibling dynamics were strained due to ongoing stress and financial burdens (Heidari & Ahmadi, 2020). Parents often found themselves juggling multiple, conflicting roles without sufficient support.

> "*My daughter's illness has made her siblings nervous, so when something happens, the other children and their father become angry and shout, no one laughs at home anymore, when someone in the house is bored, I just have to endure everything. If my husband helped me, I would feel better*" (Navabian et.al, 2021)

> *'I am not responsible for my child's disease, but my husband believes it's because of me. Now my life is not the same as it was before, I want my husband to talk to me about our child's disease and want him to go to the doctors with me, to stay with me during blood transfusion but it never happened and he put all the responsibility related to child's treatment and hospital visits on me'(Ishfaq, et al., 2015)*

Sub-theme: Supportive or absent spouse involvement
Spousal involvement emerged as a significant factor influencing parents' emotional resilience and their ability to cope with the demands of caring for a child with thalassemia. The presence of a supportive spouse provided not only practical assistance but also emotional comfort, reducing the burden of care and fostering a sense of shared responsibility within the family. In contrast, the absence of spousal support often intensified feelings of exhaustion, loneliness, and helplessness, leaving one parent—most often the mother—to bear the full emotional and physical burden of caregiving.
Some parents described their spouses as highly supportive and actively engaged in caregiving responsibilities, as reflected in the following statement:

> *"...Thankfully, he helps and actively seeks blood donors..."* (Dewi et.al, 2024)

However, others expressed deep distress over the lack of such involvement. One father shared his sense of isolation and fatigue.

> *"Sometimes I feel helpless, I feel tired. I do not even send my child go out on the street alone. I always walk behind him. My family… No one was with me, only my wife was with me…" (*Karakul et al., 2022).

Similarly, another participant emphasized the emotional toll of an unsupportive family environment.

> *"If my husband and children had helped, I would not be so sick now. At least, if they had listened to my heartache, I would have calmed down*" (Navabian, et al., 2022)

4. Meta-theme: Lack of systemic and social support, and the need for connectedness

Sub-theme: Lack of social and systemic support
Parents expressed a strong need for social and emotional support to cope with the chronic stress of caregiving. Support from spouses, extended family members, and healthcare providers played a crucial role in mitigating distress (Dewi et al., 2024; Nagiria et al., 2021).

> *"When we get here in the morning. We come by two buses. It is both costly and more tiring for us." (Karakul et al., 2022).*
> *"I am a labor worker. I earn between 12,000 and15,000 PKR per month. "Medical cost is free at the children's hospital. Mostly the transport cost and meal expenses kill us. For daily cost comes up to 1,000 to 1,500 rupees.*

> *There are a lot of times when we didn't have money, but we managed by borrowing from our close ones." (Rehman, et.al 2023)*
>
> *To provide pills we have to search everywhere. But they are not easily available, and this is very distressing." (Pouraboli, et.al, 2017)*

Sub-theme: The need for emotional and informational support

However, in many cases, parents reported a lack of consistent and reliable support systems. Limited access to iron chelation therapy, a scarce blood supply, and unresponsive healthcare services compounded their emotional and financial burdens (Abu Shosha & Al Kalaldeh, 2018; Nagiria et al., 2021)

> *"The cost of treatment has increased so much that I use only one dose of deferoxamine for my two sick children, and sometimes I do not even have the money to provide it. I do not know much about my children's problems. I take them to the local clinic and to others when they get sick, but no one guides me. I wish there were a doctor to help us. I myself need help now" (Navabian, et al., 2022)*
> *"I know that thalassemia is a genetic disorder, but I don't know why one of my daughters has the disease while the others are healthy . . . what about my next pregnancy?" (Shosha et al., 2018)*

Sub-theme: Positive external support systems

> *External social support played an essential role in helping families of children with thalassemia adapt to the demands of ongoing care. Positive interactions with individuals and institutions outside the immediate family—such as teachers, peers, community members, and public service providers—serve as valuable sources of emotional, social, and practical assistance. These external support systems help reduce the stigma often associated with chronic illness and strengthen parents' sense of belonging and acceptance within their communities.*
> *In some cases, school environments demonstrated understanding and inclusivity toward children with thalassemia. As one parent reported:*
> *"...Teachers ask for parental consent for school activities (Dewi, et.al, 2024)*

Another participant described how community empathy and awareness helped alleviate their daily struggles:

> *When we are outside from the village or at the hospital, the people stare at him and us. However, when we are in the village, he is well accepted. The teachers, students, and the community are aware of his older brothers, who had similar sicknesses and died. Therefore, they are sympathetic and empathic. That's why the PMV (public bus) rides are usually free for him when we come for blood transfusions" (Nagiria, et al., 2021)*

Sub-theme: The need for awareness and prevention

A recurring theme among parents of children with thalassemia was the recognition of the need for greater awareness and preventive education about the disease. Many parents expressed a strong desire to protect their relatives and community members from experiencing similar challenges; yet they often lacked adequate knowledge on how to explain the illness or promote preventive measures such as premarital screening and genetic counseling. This gap in awareness underscores the ongoing need for effective health education and community-based interventions. As one participant stated:

> *I want to prevent my family members and relatives from this disease, but I really do not know what exactly to tell relatives that what this disease is and what are the preventive measures to this disease' (Ishfaq et al., 2015)*

Another parent described their efforts to seek accurate information and the highlighted reassuring role of healthcare providers:

> "*While I was in the ward, I usually tried to obtain information about the disease when the doctor was not busy. The nurse (B) had time and gave us with information about thalassemia. Talking to the nurses calmed us*"(Heidari et al., 2018).

DISCUSSION

This meta-synthesis analyzed twelve qualitative studies to explore the lived experiences of parents caring for children with thalassemia, organized according to Roy's Adaptation Model (RAM). The findings confirm that caregiving in this context is a multidimensional process involving challenges across the physiological-physical, self-concept, role function, and interdependence domains. Each adaptive mode revealed not only the stressors experienced by parents but also potential pathways to enhance their adaptation and resilience through targeted nursing interventions.

The use of the RAM provided a comprehensive theoretical framework for categorizing parental responses and identifying specific areas of maladaptation. It also facilitated the development of practical implications grounded in nursing science. Through this model, the analysis contributes to a deeper understanding of the dynamic interplay among individual, familial, and systemic factors that influence caregiver well-being and the sustainability of caregiving.

Adaptation in the Physiological–Physical Mode: Physical exhaustion and psychosomatic consequences

Sub-theme: Caregiver fatigue and exhaustion

Parents, particularly mothers, consistently reported physical exhaustion, disrupted sleep, and a decline in personal health. These symptoms reflect the strain of continuous caregiving, which can compromise the regulatory subsystem described by Roy. Similar patterns have been identified in recent studies, where caregivers of children with chronic illnesses exhibited elevated rates of fatigue, poor sleep quality, and musculoskeletal complaints due to prolonged physical and emotional labor (Ault et al., 2024; Haley et al., 2020; Rico-Blázquez et al., 2021; Sloan et al., 2020). These findings underscore the need for nursing interventions that monitor and manage caregivers' physical health as part of routine pediatric care.

In many cases, caregivers deprioritize their own health needs to focus on managing their child's complex medical regimen. Over time, this neglect can lead to caregiver burnout and diminish the quality of care provided. To support effective physiological adaptation, nurses should incorporate caregiver health assessments, provide information on managing physical stress, and advocate for respite care services (Ahmadi et al., 2021; Becqué et al., 2019; Boisvert, Zubatsky, & Berg-Weger, 2022), particularly in low-resource settings where professional support is limited. This finding aligns with studies by Ault et al. (2024) and Toledano-Toledano et al. (2021), who similarly reported high rates of caregiver fatigue in chronic pediatric conditions. However, unlike caregivers of children with autism or cancer, thalassemia caregivers face unique challenges related to regular blood transfusion logistics and iron chelation therapy, which intensify physical demands (Ault et al., 2024; Toledano-Toledano et al., 2021).

Adaptation in the Self-Concept Mode: Psychological distress and parental identity crisis

The diagnosis and lifelong nature of thalassemia often disrupt in the parents' self-concept, manifesting as guilt, self-blame, shame, and emotional exhaustion. Parents from cultures where genetic illness are stigmatized experience heightened distress, particularly when they believe their actions or family history have caused their child's suffering (Islam et al., 2025; Jamil, Ejaz, Najeeb, , & Jamil, 2024; Purwoko et al., 2022; Sahu et al., 2023). Roy's self-concept mode explains how maladaptive internal perceptions and external stigmatization impair adaptive functioning.

Recent studies also highlight the link between emotional overload and impaired coping capacity among caregivers (Amirah, Rakhmilla, , & Sari, 2021; Angane et al., 2022; Batool et al., 2021; Bhandari et al., 2022; Othman et al., 2022). To improve self-concept adaptation, nurses should provide psychoeducation about the genetic nature of thalassemia, alleviate guilt through therapeutic communication, and implement culturally tailored emotional resilience programs (Ahmadian et al., 2024; Ansari et al., 2024; Narenjbaghi, Valizadeh, Zamanzadeh, Ghahramanian, & Asghari-Jafarabadi, 2025; Palanisamy et al., 2024; Yasmeen et al., 2024). Creating safe spaces for emotional expression and peer support can also mitigate the psychological toll of caregiving. For instance, support groups specifically for parents of children with thalassemia, as explored by Palanisamy et al. (2024), have demonstrated efficacy in reducing isolation and self-blame, contrasting with the persistent distress observed in settings lacking such interventions (Heidari & Ahmadi, 2020; Palanisamy et al., 2024).

Adaptation in the Role Function Mode: Role disruption and Challenges in family functioning

Caregiving responsibilities significantly disrupted parents' ability to fulfill their social, familial, and professional roles. Many were forced to reduce their working hours or quit their jobs entirely, while others experienced strain in their marital relationships or conflicts in parenting their other children (Islam et al., 2025; Sahu et al., 2023; Yasmeen et al., 2024). According to the RAM, this reflects role insufficiency—when individuals are unable to meet role expectations due to resource limitations or emotional overload. These findings emphasize the impact of chronic illness on family role dynamics, particularly in traditional settings where caregiving is often considered a maternal obligation (Chirani et al., 2025).

Support for role function adaptation must include family-centered interventions that validate the caregiver's experience and encourage role reflection. Nurses can facilitate caregiver role support through multidisciplinary collaboration, flexible appointment scheduling, and family education sessions that address sibling involvement and spousal communication. These recommendations are supported by Maleki et al. (2022) but contrast with findings from Chirani et al. (2025), who noted that in highly patriarchal societies, role redistribution remains challenging despite nursing interventions. This highlights the need for culturally nuanced approaches (Chirani et al., 2025; Maleki et al., 2022).

Adaptation in the Interdependence Mode: The lack of systemic and social support, and the need for connectedness

Parental experiences within the interdependence mode revealed mixed findings. Some parents benefited from supportive relationships with spouses, extended family, or religious communities, while others faced social isolation and emotional neglect. Inconsistent access to healthcare, blood transfusions, and information was also frequently reported (Chen et al., 2024; Day et al., 2024; Wong et al., 2024). These challenges reflect maladaptive interdependence, as described in Roy's model, where a lack of supportive relationships hinders effective coping. As described in Roy's model, a lack of supportive relationships hinders the ability to cope effectively. In contrast, adaptive interdependence was observed among parents who actively sought and received sustained support from spouses, religious communities, or peer networks, which facilitated better emotional regulation and continuity of care.

Recent advances in digital health and social media have opened new avenues for enhancing interdependence. Online peer groups, mobile health applications, and virtual caregiver networks have been shown to reduce caregiver isolation and increase access to practical and emotional support (El Kheir et al., 2025; Mojtahedi, Shen, 2024; Stanley et al., 2024; Tang, Huang, Liu, & Kim, 2020; Yeo et al., 2025). Nurses should recommend reliable digital resources and facilitate community-based peer support programs, especially in rural and underserved areas. Culturally embedded community health workers may also serve as valuable bridges between families and healthcare systems. For example, community health worker programs in rural Iran (Ahmadian et al., 2024) have successfully improved care coordination, whereas in Papua New Guinea, the absence of such bridges exacerbated family isolation (Nagiria et al., 2021).

Implications for Nursing Practice

This synthesis suggests that holistic nursing care for families affected by thalassemia must integrate all four adaptive modes of the RAM. Nurses are well-positioned to assess caregiver burden, identify maladaptive responses, and design interventions that promote sustainable caregiving. This approach includes combining clinical care with psychoeducation, role counseling, and culturally sensitive communication. Recognizing caregivers as central members of the care team ensures that their needs are acknowledged and addressed.

Nurses can implement routine caregiver screenings using tools based on the RAM, establish support networks, and develop individualized care plans that consider the entire family system. Training in culturally competent and family-centered care should be integrated into nursing curricula and continuing professional education to support this model across diverse contexts. Strengthening nurse-led interventions will also improve family resilience and the quality of care for children with thalassemia.

Study limitations

This meta-synthesis has several limitations that should be considered when interpreting the findings. First, although the included studies were selected from diverse countries and cultural settings, most were conducted in Asia and the Middle East. This geographic concentration may limit the generalizability of the results to Western or African contexts, where parental experiences and health systems may differ substantially.

Second, the analysis was limited to studies published in English between 2014 and 2024. This language restriction may have excluded relevant studies published in other languages, which could provide additional insights into caregiving experiences.

Third, the synthesis relied on the original authors' thematic interpretations because full access to the raw interview transcripts was unavailable. This limitation may have constrained the depth of the secondary analysis and could have introduced interpretive bias.

Lastly, while Roy's Adaptation Model provided a useful framework for categorizing the findings, relying on a single theoretical lens may have overlooked other aspects of parental experiences that fall outside the scope of this model. Future research should consider employing multiple theoretical perspectives to better capture the complexity of caregiving adaptation.

CONCLUSION AND RECOMMENDATIONS

This meta-synthesis highlights the multidimensional challenges experienced by parents of children with thalassemia, which can be systematically understood through Roy's Adaptation Model. Parents encounter significant adaptive demands across four modes: physical strain from caregiving routines, emotional burden and identity conflict, disruption of familial roles, and insufficient social support. These findings underscore that parental adaptation is a dynamic and ongoing process, characterized by both adaptive and maladaptive responses within Roy's four modes. This process is profoundly influenced by personal resilience, cultural norms, and access to healthcare resources, highlighting the need for continuous, multidimensional support systems.

In summary, the meta-synthesis reveals that parents of children with thalassemia major undergo a multidimensional adaptation process characterized by both resilience and vulnerability. While some parents adapt positively through spiritual strength and social support, seen demonstrated studies from Indonesia (Dewi et al., 2024) and Iran (Heidari et al., 2018), others experience maladaptive responses such as emotional exhaustion, depression, and physical deterioration. The Roy Adaptation Model offers a holistic theoretical lens framework to understand the complexity of these caregiving experiences and highlights areas where nursing and psychosocial interventions may are needed.

For nursing practice, this study affirms the importance of holistic, family-centered care. Nurses should routinely assess parental adaptation using frameworks such as the RAM and provide targeted interventions to support each adaptive mode. These interventions may include health education, psychosocial support, guidance on role negotiation, and the facilitation of peer or community support groups.

For nursing education, the findings advocate incorporating family adaptation theories and caregiver support strategies into nursing curricula to better prepare nurses to provide comprehensive care for families of chronically ill children.

For future research, longitudinal and cross-cultural studies are necessary to further investigate the dynamic process of adaptation and to evaluate the effectiveness of RAM-based nursing interventions in supporting parental well-being and sustaining caregiving.

By understanding and addressing the adaptive challenges faced by parents, nurses can enhance both the quality of care for children with thalassemia and the overall health outcomes of their families.

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